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**LEUKEMIA &
LYMPHOMA
SOCIETY®**

fighting blood cancers

The AML Guide

Information for Patients and Caregivers

Acute Myeloid Leukemia



Emily, AML survivor

A Message from Louis J. DeGennaro, PhD

President and CEO of The Leukemia & Lymphoma Society

The Leukemia & Lymphoma Society (LLS) wants to bring you the most up-to-date blood cancer information. We know how important it is for you to understand your treatment and support options. With this knowledge, you can work with members of your healthcare team to move forward with the hope of remission and recovery.

Our vision is that one day most people who have been diagnosed with acute myeloid leukemia (AML) will be cured or will be able to manage their disease and have a good quality of life. We hope that the information in this *Guide* will help you along your journey.

LLS is the world's largest voluntary health organization dedicated to funding blood cancer research, advocacy and patient services. Since the first funding in 1954, LLS has invested more than \$814 million in research specifically targeting blood cancers. We will continue to invest in research for cures and in programs and services that improve the quality of life for people who have AML and their families.

We wish you well.

A handwritten signature in black ink, appearing to read 'Louis J. DeGennaro', with a long horizontal flourish extending to the right.

Louis J. DeGennaro, PhD

*President and Chief Executive Officer
The Leukemia & Lymphoma Society*

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This LLS Guide about AML is for information only. LLS does not give medical advice or provide medical services.

Introduction

Acute myeloid leukemia (AML) is a type of blood cancer. Another name for AML is acute myelogenous leukemia. AML is the most common acute leukemia affecting adults.

Remission rates for people who have AML are improving. Remission means that there is no sign of AML cells in the blood or marrow and blood cell counts are back to normal. But more work needs to be done. New treatment approaches are under study. There are new treatment studies (called **clinical trials**) for patients

- With all types of AML
- Of all ages and in all stages of treatment.

More information about clinical trials begins on page 24.

About 12,950 people in the United States were expected to be diagnosed with AML in 2011.

About 30,993 people in the United States are living with, or are in remission from, AML.

Many people want to know what questions to ask their doctor. They may want information about choosing a specialist or about treatment. This *Guide* includes a list of suggested questions to ask the doctor (see the insert in the pocket on the inside back cover). There are also other healthcare question guides you can print. Go to www.LLS.org/whattoask or contact our Information Specialists for copies.

Some words in the *Guide* may be new to you. Check *Medical Terms* beginning on page 31. Or, call our Information Specialists at (800) 955-4572.

Want more information?



You can view, print or order the free LLS publications *Understanding Leukemia* and *Acute Myeloid Leukemia* at www.LLS.org/resourcecenter or contact our Information Specialists for copies.

Here to Help

The information in this *Guide* will help you when you talk to your doctor about tests and treatment. Members of your healthcare team will also answer your questions and give support and any needed referrals. Let your doctor know if you want a professional healthcare interpreter who speaks your native language or uses sign language. Many times, this is a free service.

The news that you have AML may be a shock to you and your loved ones. You may feel sad, depressed or afraid. Keep in mind that

- Many people can cope better once they begin treatment and can look forward to recovery.
- The outlook for people with AML continues to improve.
- New treatments are being studied in clinical trials for patients of all ages and in all stages of treatment.

LLS Has Ways to Help. Treatment for AML will affect your daily life for a time. You may want to ask friends or family members to help you

- Get information
- Take care of chores.

We want you to know that LLS offers free information and patient services for individuals and families touched by blood cancers.

Information Specialists. Our Information Specialists are master's level professionals. They provide up-to-date blood cancer information. You

can call to speak with an Information Specialist Monday through Friday, 9 a.m. to 6 p.m. ET at (800) 955-4572. You can also email infocenter@LLS.org or chat online at www.LLS.org.

Language Services. Free language services are available for calls with our Information Specialists.

Free Materials and Información en Español. LLS has free patient education and support booklets in English and Spanish. You can order booklets by phone at (800) 955-4572. You can also read or print the booklets, or order free print versions, at www.LLS.org/resourcecenter.

Chapter Programs and Services. LLS chapter offices around the United States and Canada offer support and education. Your chapter can arrange for you to speak to another person living with a similar type of AML through the *Patti Robinson Kaufmann First Connection Program*. The *Patient Financial Aid* program offers a limited amount of financial aid for qualified patients. Find your local chapter by calling (800) 955-4572 or by visiting www.LLS.org.

Clinical Trials. Our Information Specialists help patients work with their doctors to find out about specific clinical trials. You can also use **TrialCheck**[®], an online clinical-trial search service supported by LLS. TrialCheck offers patients and caregivers immediate access to listings of blood cancer clinical trials. You can reach this online service by visiting www.LLS.org/clinicaltrials.

Telephone/Web Education Programs. LLS provides free telephone and web education programs by experts for patients and caregivers. For more information contact our Information Specialists or visit www.LLS.org/programs.

The Trish Greene Back to School Program for Children With Cancer. This program helps doctors, nurses, parents and school personnel work together for a smooth return to school for children with cancer. For more information contact your local LLS chapter or call (800) 955-4572.

Reach Out. You and your loved ones can reach out to others for support. For example:

- LLS offers online Blood Cancer Discussion Boards and online chats at www.LLS.org/getinfo.
- Local or Internet support groups and blogs can give support.
- You may get to know other people living with cancer. These friendships provide support.

Suggestions From Other People Living With Cancer

- Get information about choosing a cancer specialist or treatment center.
- Talk with family and friends about how you feel and how they can help you.
- Find out what your insurance covers.
- Find out if financial assistance is available.
- Learn about the most current tests and treatments for your type of AML.
- Talk openly with the doctor about your fears or concerns.
- Tell your doctor if you have any side effects of treatment.
- Contact your doctor if you have fatigue, fever, pain or sleep problems.
- Get medical advice if you have changes in mood or feelings of sadness or depression.

We'd Like to Hear From You. We hope this *Guide* helps you. Please tell us what you think at www.LLS.org/publicationfeedback. Click on **LLS Disease & Treatment Publications—Survey for Patients, Family and Friends.**

Part 1—Understanding AML

Leukemia is the general term for some different types of blood cancer. AML is one of four main types of leukemia.

About Marrow, Blood and Blood Cells

The information on this page about normal blood and marrow may help you understand the AML information in the rest of this *Guide*.

Marrow is the spongy center inside of bones where blood cells are made.

Blood cells are made in the marrow. They begin as stem cells. Stem cells become red cells, white cells and platelets in the marrow. Then the red cells, white cells and platelets enter the blood.

Platelets form plugs that help stop bleeding at the site of an injury.

Red cells carry oxygen around the body. When the number of red cells is below normal, the condition is called **anemia**. Anemia may make you feel tired or short of breath. It may make the skin look pale.

White cells fight infection in the body. There are two major types of white cells: germ-eating cells (neutrophils and monocytes) and infection-fighting “lymphocytes” (B cells, T cells and natural killer [NK] cells).

Plasma is the liquid part of the blood. It is mostly water. It also has some vitamins, minerals, proteins, hormones and other natural chemicals in it.

About AML

AML is a type of cancer that begins in the bone marrow. The chance of getting AML increases with age. But a person can get AML at any age. About 8 in 10 adults with acute leukemia have AML. About 1 in 6 children with leukemia has AML.

Normal Blood Cell Count Fast Facts

The ranges of blood cell counts below are for adults. They may be a little different from lab to lab and for children and teens.

Red blood cell (RBC) count

- Men: 4.5 to 6 million red cells per microliter of blood
- Women: 4 to 5 million red cells per microliter of blood

Hematocrit (the part of the blood made up of red cells)

- Men: 42% to 50%
- Women: 36% to 45%

Hemoglobin (amount of the red cell pigment that carries oxygen)

- Men: 14 to 17 grams per 100 milliliters of blood
- Women: 12 to 15 grams per 100 milliliters of blood

Platelet count

- 150,000 to 450,000 platelets per microliter of blood

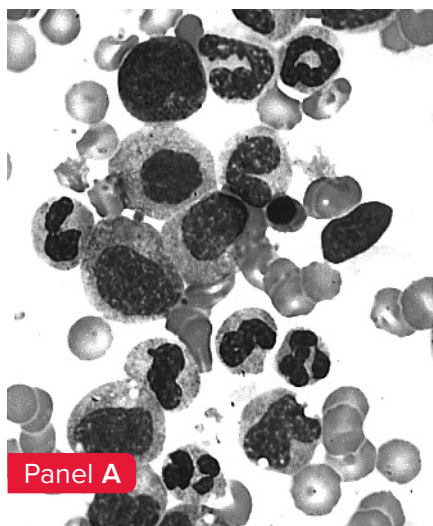
White blood cell (WBC) count

- 4,500 to 11,000 white cells per microliter of blood

Differential (also called diff)

- Shows the part of the blood made up of different types of white cells
- The types of white cells counted are neutrophils, lymphocytes, monocytes, eosinophils and basophils.
- Adults usually have about 60% neutrophils, 30% lymphocytes, 5% monocytes, 4% eosinophils and less than 1% basophils in the blood.

Normal Marrow Cells and AML Blast Cells



Panel A



Panel B

The cells in panels A and B are shown much larger than actual size. The cells are also stained with a special dye so that they can be seen more clearly.

Panel A shows different types of normal marrow cells seen through a microscope. These normal cells are in various stages of development.

Panel B shows AML blast cells seen through a microscope. These cells have stopped developing.

Causes and Risk Factors of AML. AML starts with a change to a single cell in the bone marrow. Doctors do not know what causes most cases of AML. There is no way to prevent AML. You can't catch AML from someone else.

Certain things may increase the risk of getting AML, such as

- Some types of chemotherapy
- Radiation used to treat cancer
- Down syndrome
- Tobacco smoke
- Repeated contact with the chemical benzene.

Benzene can harm normal marrow cells. The majority of benzene in the environment comes from petroleum products, however, half of

the personal exposure is from cigarette smoke. The average smoker is exposed to about 10 times the daily intake of benzene compared to nonsmokers. Benzene is also found in some work settings. But, strict rules have led to lowered amounts of benzene in the workplace.

Most people with the risks listed on page 8 do not get AML.

Signs and Symptoms. Many of the signs and symptoms of AML are also caused by other types of illness. Most people with these signs and symptoms do not have AML.

A *sign* is a change in the body that the doctor sees in an exam or a test result.

A *symptom* is a change in the body that the patient can see or feel.

Some Signs and Symptoms of AML

Not feeling well

| Having fewer normal bone marrow cells may cause aches in the legs, arms or hips. Patients may have a mild fever, enlarged lymph nodes or swollen gums.

Tiring more easily, shortness of breath, pale skin color

| Having fewer healthy red cells may lower energy levels. It may also make people feel short of breath while doing day-to-day activities. Some people with fewer red cells may have a pale skin color.

Weight loss

| Some people with AML lose weight because they eat less and/or they use more energy.

Black-and-blue marks or pinhead-sized red spots

| A low platelet count may cause patients to bruise more easily or to have tiny red spots called **petechiae** on the skin.

Bleeding for a long time from minor cuts

| A low platelet count may lead to a longer bleeding time or slower healing of cuts.

Diagnosis

It is important for patients to receive the right diagnosis. AML is diagnosed with blood and bone marrow tests.

Blood Cell Counts. The doctor orders a test called a **CBC** (complete blood count) to count the numbers of red cells, white cells and platelets. Usually, patients with AML have lower-than-expected numbers of red blood cells and platelets.

Blood Cell Examination. The cells are stained (dyed) and looked at through a microscope. This test is also called a **blood smear**. A person with AML usually has too many leukemic blast cells in the blood. These cells do not function like normal cells.

Bone Marrow Tests. Your doctor will also do other tests to make sure the diagnosis of AML is right. Tests called **bone marrow aspiration** and **bone marrow biopsy** are done to find out the percentage of AML cells in the marrow. A person with AML usually has at least 20 percent AML cells.

Types of AML

Knowing the patient's AML type helps the doctor to plan treatment. Most people with AML have one of the eight AML types: **MO**, **M1**, **M2**, **M3**, **M4**, **M5**, **M6** or **M7**. Most types of AML are treated in the same way. But patients with type M3 (acute promyelocytic leukemia, or APL for short) need a different treatment plan. More information about APL treatment is on page 21.

Flow Cytometry. Your doctor will order a test called **flow cytometry** to find out the type of AML you have.

Cytogenetic Analysis. Other tests are done to look for genetic changes in your AML cells. This examination of AML cells is called **cytogenetic analysis**. The results help your doctor to plan your treatment.

Want more information?



You can view, print or order the free LLS publication *Understanding Lab and Imaging Tests* at www.LLS.org/resourcecenter or contact our Information Specialists for a copy.

Part 2—Treatment

Choosing a Specialist

Choose a doctor who specializes in treating AML and knows about the most up-to-date treatments. This type of specialist is usually called a **hematologist/oncologist**. Or, your local cancer specialist can work with an AML specialist.

Ways to Find an AML Specialist

- Ask your primary care doctor.
- Contact your community cancer center.
- Call your local medical society.
- Reach out to doctor and/or health plan referral services.
- Call LLS for a list of cancer centers or go to www.LLS.org/cancercenters.
- Use online doctor-finder resources, such as
 - The American Medical Association’s (AMA) “DoctorFinder”
 - The American Society of Hematology’s (ASH) “Find a Hematologist.”

Want more information?



You can view, print or order the free LLS publication *Choosing a Blood Cancer Specialist or Treatment Center* at www.LLS.org/resourcecenter or contact our Information Specialists for a copy.

Ask Your Doctor

Talk with the doctor about how he or she plans to treat your AML. This will help you to be actively involved in your care and to make decisions. This *Guide* includes questions to ask your doctor about AML treatment (see “Questions to Help You Choose a Specialist” in the pocket on the inside back cover).

It may be helpful to write down the answers to your questions and review them later. You may want to have a caregiver, family member or friend with you when you talk to your doctor. This person can listen, take notes and offer support. Some people like to record information from the doctor and then listen to the recording later on.

People with AML who are unsure about their treatment options may want to get a second opinion.

Treatment Planning

The goal of treatment for AML is to cure the disease.

- Almost half of children with AML are cured.
- Patients with acute promyelocytic leukemia (APL) have higher cure rates overall compared to adults with other AML types.
- Some adults with other types of AML may be cured or have long periods of remission.
- There has been improvement in treatment outcomes for people with all types of AML.

Some things that may affect the outcome of your AML treatment are

- Your type of AML
- The results of your lab tests
- Your age and general health
- Your medical history, including whether you
 - Were treated with chemotherapy before for another type of cancer
 - Had a myelodysplastic syndrome (MDS)
- Whether you have
 - A serious infection at the time of diagnosis
 - AML in your central nervous system
 - AML that has not responded to treatment or has relapsed.

It is important to talk to your doctor about the results of your bone marrow examination. This test provides information about the marrow cells that is needed for treatment planning. It is also important to talk to your doctor about molecular and genetic tests.

Want more information?



For a list of questions to ask your doctor, see the inserts in the back pocket of this *Guide*. You can also access and print *Healthcare Question Guides* about second opinions and other topics at www.LLS.org/whattoask or contact our Information Specialists for copies.

Fast Facts About AML Treatment

- Some patients who have AML are cured with treatment.
- Many patients with AML need treatment as soon as possible after diagnosis.
- An AML patient is usually treated by a hematologist/oncologist.
- AML patients should be treated by doctors who are skilled in treating patients with AML.
- The treatment plan for each patient is based on his or her AML test results.
- The initial goal of treatment is usually to get the patient into remission.
- A remission means: There is no sign of AML cells in the blood or marrow; blood cell counts are back to normal.
- Many older patients can be treated for AML and enter remission.
- Most patients need chemotherapy to achieve remission. At least two drugs are combined to treat patients. This is called **induction therapy**.
- More treatment is needed once a remission is achieved to help prevent a relapse. This is called **postremission therapy**.
- Postremission therapy may consist of chemotherapy, stem cell transplantation or low-dose maintenance chemotherapy.
- Patients may have a return of AML after treatment. This is called a **relapse**.

About AML Treatments

Treatment for patients with AML (or relapsed AML) may include

- Chemotherapy
- Stem cell transplantation
- New approaches under study (clinical trials).

A patient may receive different drugs from those described in this *Guide* and still be receiving proper treatment.

Speak to your doctor to find out what treatment is best for you. Our Information Specialists can help you plan questions to ask your doctor about treatment.

Induction Therapy. Induction therapy is the first part of treatment with chemotherapy. Most AML patients need to start induction chemotherapy right away. Induction therapy is done in the hospital. Patients are often in the hospital for 4 to 6 weeks for this first part of treatment.

The aims of induction therapy are to

- Kill as many AML cells as possible
- Get blood counts back to normal
- Get rid of all signs of the disease for an extended period of time.

Chemotherapy and other drugs. Chemotherapy drugs and other types of drugs kill or damage cancer cells. Several types of drugs are used to kill AML cells. Each drug type works in a different way. Combining the drugs can make the treatment work better.

Want more information?



You can view, print or order the free LLS publication *Acute Myeloid Leukemia* at www.LLS.org/resourcecenter or contact our Information Specialists for a copy.

The first round of chemotherapy usually does not get rid of all the AML cells. Most patients will need more rounds of therapy. Usually the same drugs are used for the added rounds needed to complete induction therapy.

When there is no sign of AML, this is called a **remission**.

Some drugs are given by mouth. Other drugs are given through a central line, port or PICC. Medications, nutrition and blood products can all be administered via central lines or PICCs. Blood for lab tests can also be withdrawn via these lines. Central lines, ports and PICCs can stay in place for weeks or months. You can talk to your doctor about the best one for you or your child to use.

Central Lines, Ports and PICCs

Central Line

This is a thin tube that is put under the skin and into a large vein in the chest. The central line stays firmly in place. **Catheter** is another word for central line.

Port

This is a small device that is used with a central line. The port is placed under the skin of the chest. After the site heals, no dressings are needed and no special home care is needed. To give medicines or nutrition or to take blood samples, the doctor or nurse puts a needle through the skin into the port. A numbing cream can be put on the skin before the port is used.

PICC or PIC Line

PICC or PIC line is short for percutaneously inserted central venous catheter. A PICC is inserted through a vein in the arm.

Some of the drugs used to treat AML are listed on page 17. These are some of the standard drugs used and some of the drugs under study in AML clinical trials.

Some Drugs Used to Treat AML

Drug Types	Drug Names
Anthracyclines (Antitumor Antibiotics)	daunorubicin (Cerubidine®); doxorubicin (Adriamycin®); idarubicin (Idamycin®); mitoxantrone (Novantrone®)
Antimetabolites	cladribine (2-CdA; Leustatin®); clofarabine (Clolar®); cytarabine (cytosine arabinoside, ara-C; Cytosar-U®); fludarabine (Fludara®); hydroxyurea (Hydrea®); methotrexate; 6-mercaptopurine (Purinethol®); 6-thioguanine (Thioguanine Tabloid®)
Topoisomerase Inhibitors	etoposide (VP-16; VePesid®, Etopophos®); topotecan (Hycamtin®)
DNA Damaging (Alkylating) Agents	cyclophosphamide (Cytosan®); carboplatin (Paraplatin®); temozolomide (Temodar®)
Cell-Maturing Agents	all- <i>trans</i> retinoic acid (ATRA, tretinoin; Vesanoïd®); arsenic trioxide (Trisenox®)
Hypomethylating Agents	azacitidine (Vidaza®); decitabine (Dacogen®)

Want more information?



You can view, print or order the free LLS publication *Understanding Drug Therapy and Managing Side Effects* at www.LLS.org/resourcecenter or contact our Information Specialists for a copy.

Radiation Therapy

Sometimes radiation therapy may be used to treat a large mass of AML cells in the spine or brain called a **chloroma**.

Postremission Therapy. More treatment is usually needed even after an AML patient is in remission. Some AML cells may remain that are not found by common blood or marrow tests. This part of AML treatment is called **postremission therapy** or **consolidation therapy**.

Chemotherapy is part of postremission therapy for AML. Stem cell transplantation may be part of postremission therapy for some AML patients.

The treatment setting (hospital or outpatient) and the length of hospital stay depend on the postremission treatment. The length of time in the hospital also depends on any side effects of treatment. Patients are often in the hospital for 4 to 6 weeks. Some patients may need to be in the hospital longer.

Relapsed or Refractory AML

Some patients have a remission after treatment, but then AML cells return later (a relapse). Patients may have AML cells in the marrow even after treatment (refractory AML).

Patients who relapse may be treated with the same drugs as newly diagnosed patients—or different drugs may be given. Patients who have a matched donor may be given an allogeneic stem cell transplant. Information about allogeneic stem cell transplantation begins on page 19.

With refractory AML, drugs that were not used in the first round of treatment may be given. An allogeneic transplant may also be a part of treatment.

Stem Cell Transplantation

Your doctor will talk with you about whether stem cell transplantation is a treatment option for you. Information about different types of transplants is on the next few pages.

Allogeneic Stem Cell Transplantation. An allogeneic transplant uses stem cells from a donor. The donor may be a brother or sister. Or, the donor can be an unrelated person with stem cells that “match” the patient’s. Stem cells may also come from a cord blood unit (the blood in the umbilical cord after a baby’s birth).

The goals of an allogeneic transplant are to

- Restore the body’s ability to make normal blood cells after high-dose chemotherapy
- Cure the patient of his or her AML by killing any remaining AML cells.

Allogeneic transplants may be done in the hospital. First, the patient is given high-dose chemotherapy and/or radiation therapy. Stem cells are collected from a donor. The donor stem cells are given to the patient through an IV (intravenous) line or central line. The donor stem cells go from the patient’s blood to the marrow and help start a new supply of red cells, white cells and platelets.

Your doctor will talk with you about whether an allogeneic transplant is a treatment option for you.

Allogeneic stem cell transplantation is a high-risk procedure. Doctors are working to make allogeneic transplants safer. An allogeneic transplant may be a choice for an AML patient if

- He or she has a type of AML that is hard to treat.
- The expected benefits of an allogeneic transplant exceed the risks.
- There is a stem cell donor.

The upper age limit for an allogeneic transplant depends on the treatment center. Many centers use age 60 or 65 years as the upper age limit for an allogeneic transplant.

Your doctor will talk to you about whether a reduced-intensity allogeneic stem cell transplant is a treatment option for you. The goal of a reduced-intensity transplant is to cure the patient of his or her AML. A reduced-intensity allogeneic transplant uses lower doses of chemotherapy than a standard allogeneic transplant. Some older and sicker patients may be helped by this treatment. Many centers use 70 years or older as the upper age limit for a reduced-intensity allogeneic transplant.

A reduced-intensity allogeneic transplant may be a choice for an AML patient if

- He or she has a type of AML that is hard to treat.
- A standard allogeneic transplant is not a choice because of the patient's age or overall health.
- The expected benefits of a reduced-intensity allogeneic transplant exceed the risks.
- There is a stem cell donor.

Autologous Stem Cell Transplantation. An autologous transplant uses the patient's own stem cells.

The goal of an autologous transplant is to restore the body's ability to make normal blood cells after high-dose chemotherapy.

The patient's own blood or marrow stem cells are stored before chemotherapy begins. They are infused back into the patient's blood after chemotherapy ends. The stem cells are given back to the patient through an IV (intravenous) line or central line. The stem cells go from the patient's blood to the marrow and help start a new supply of red cells, white cells and platelets.

Your doctor will talk with you about whether an autologous transplant is a treatment option for you. Patients who have not responded well to treatment and do not have a matched donor for an allogeneic transplant may be given very high doses of chemotherapy and an autologous transplant.

Want more information?



You can view, print or order the free LLS publications *Blood and Marrow Stem Cell Transplantation* and *Cord Blood Stem Cell Transplantation* at www.LLS.org/resourcecenter or contact our Information Specialists for copies.

Acute Promyelocytic Leukemia (APL) Treatment

APL is the M3 subtype of acute myeloid leukemia (AML). It is the most curable subtype of AML. Patients with APL need different treatment than patients with other AML subtypes.

APL patients are treated with the drug all-*trans* retinoic acid (ATRA). ATRA is also called tretinoin (Vesanoid®). ATRA alone can lead to a short-term remission in many patients. But ATRA given with chemotherapy helps many patients to have long-lasting remissions.

APL patients with a very high white cell count at diagnosis may need more chemotherapy than other patients.

Arsenic trioxide (Trisenox®) is another drug used to treat some APL patients. Arsenic trioxide may be given to patients who are not in remission (or do not stay in remission) after treatment with ATRA and chemotherapy.

Some high-risk APL patients may be treated with an allogeneic stem cell transplant if a matched stem cell donor is available. Patients who do not have a donor, or cannot have an allogeneic stem cell transplant for other

reasons, may be candidates for an autologous stem cell transplant. Stem cell transplant information is on pages 18 to 21.

All patients treated for AML, including patients with APL, need long-term follow-up. Some patients may require further therapy.

Acute Monocytic Leukemia Treatment

Acute monocytic leukemia is the M5 type of acute myeloid leukemia (AML). AML cells can invade the lining of the spinal canal or brain. This complication is uncommon for most types of AML. But, the risk is greater for patients with acute monocytic leukemia.

A common medical procedure called a **lumbar puncture** (also called a **spinal tap**) is used to check the spinal fluid for AML cells. This procedure is done while the patient is sedated or has been given local anesthesia. A needle is placed into the spinal canal. Then, the spinal fluid is removed and checked for AML cells.

The spinal cord and brain are parts of the body that aren't easily reached with IV chemotherapy. So, if AML cells are found there, fluid containing drugs, usually cytarabine or methotrexate, is injected into the spinal canal to kill the AML cells.

After treatment, lumbar punctures are done from time to time to check whether the AML cells are being killed.

AML Treatment in Children

There are about 3,811 new cases of leukemia each year in the United States in children younger than 15 years. About 4 out of 5 children with AML go into remission. Over half of children with AML have no signs of disease after 5 years. More than half of these children are considered cured.

Induction therapy for children with AML starts with two or three drugs. More treatment is needed after a child with AML is in remission (postremission therapy). It is given because some AML cells may remain after induction therapy. These AML cells do not show up in standard blood or marrow tests. Postremission therapy in children includes a number of chemotherapy drugs.

AML treatment is less likely to bring about a remission or cure in children

- With very high white cell counts
- Younger than 2 years old
- With certain chromosome changes in their AML cells.

Allogeneic stem cell transplantation may be used in children who are not doing well or whose AML returns after high-dose chemotherapy. Doctors will discuss the benefits and risks of allogeneic transplantation with parents and older children.

Want more information?



You can view, print or order the free LLS publications *Coping With Childhood Leukemia and Lymphoma*; *Learning & Living With Cancer—Advocating for your child's educational needs*; *Pictures of My Journey*; and *The Stem Cell Transplant Coloring Book* at www.LLS.org/resourcecenter or contact our Information Specialists for copies.

AML Treatment in Older Patients

AML is more common in older patients. At least half of patients are over 65 years old when their disease is diagnosed.

Today, remissions are possible for some older people with AML, including those who may have other serious health problems. But treatment results in adults are not as good as treatment results in children.

Some healthy older patients can be treated with the same doses of chemotherapy as younger adults. Sometimes older patients have other medical problems, such as heart disease, kidney or lung disease or diabetes. The doctor takes these other medical problems into account to decide which drugs to use and in what dosage.

The doctor will also consider

- The type of AML
- The patient's physical ability to handle the treatment
- The patient's feelings about the treatment approach.

Some older patients may have a reduced-intensity allogeneic stem cell transplant. See page 20 for more information.

Part 3—About Clinical Trials

There are new treatments under study for AML patients of all ages. New treatments are studied in clinical trials. Clinical trials are also used to study new uses for approved drugs or treatments. For example, changing the amount of the drug or giving the drug along with another type of treatment might be more effective. Some clinical trials combine drugs for AML in new sequences or dosages.

There are clinical trials for

- Newly diagnosed AML patients
- Patients who do not get a good response to treatment
- Patients who relapse after treatment.

A carefully conducted clinical trial may provide the best available therapy.

Ask your doctor if treatment in a clinical trial is right for you or your child. You can also call our Information Specialists for information about clinical trials, or use our free clinical-trial service at www.LLS.org/clinicaltrials.

Want more information?



You can view, print or order the free LLS publication *Knowing All Your Treatment Options* at www.LLS.org/resourcecenter or contact our Information Specialists for a copy.

Part 4—Side Effects and Follow-Up Care

Side Effects of AML Treatment

The term **side effect** is used to describe the way that treatment affects healthy cells.

The aim of treatment for AML is to kill AML cells. Treatment for AML also affects healthy cells. Side effects of AML treatment may be severe, but they usually go away once treatment ends. Ask your doctor about the side effects to expect from your treatment.

AML treatment may affect your blood cell counts.

- The number of red cells may decrease (anemia). Red cell transfusions (red cells that are donated and given to the patient) may be needed to increase red cell counts.

- Patients may also have a drop in the number of platelets. A platelet transfusion may be needed to prevent bleeding if a patient's platelet count is very low.
- A big drop in the number of white cells may lead to an infection. These infections are usually treated with antibiotics.

Fever or chills may be the only signs or symptoms of infection. Patients with an infection may also have

- Coughing
- Sore throat
- Pain when urinating
- Frequent, loose bowel movements.

Growth factors are sometimes given to increase the number of white cells. G-CSF (Neupogen®) and GM-CSF (Leukine®) are drugs that increase white cell counts.

Growth factors are only given to children in certain cases. Researchers are studying which children with AML are most likely to be helped by treatment with growth factors to prevent infection.

To lower the risk of infection

- The patient, the patient's visitors and medical staff need to wash their hands well.
- The patient's central line must be kept clean.
- Patients should take good care of their teeth and gums.

The doctor may talk about the absolute neutrophil count or ANC, which is the number of neutrophils (a type of white cell) a person has to fight an infection.

Other Treatment Side Effects. Chemotherapy affects the parts of the body where new cells form quickly. This includes the inside of the

mouth and bowel and the skin and hair. The side effects listed here are common during chemotherapy:

- Mouth sores
- Diarrhea
- Hair loss
- Rashes
- Nausea
- Vomiting.

Not all patients have these side effects. Treatment to prevent or manage nausea, vomiting, diarrhea and other side effects can help patients feel more comfortable.

Chemotherapy may cause the amount of uric acid to increase in the blood of some AML patients. (Some patients also have a buildup of uric acid from the disease itself.) Uric acid is a chemical made in the body. A high level of uric acid can cause kidney stones.

Patients with high uric acid levels may be given a drug called allopurinol (Aloprim®, Zylprim®) by mouth. Another drug used to treat high uric acid levels is called rasburicase (Elitek®), which is given intravenously (IV).

Want more information?



You can view, print or order the free LLS publication *Understanding Drug Therapy and Managing Side Effects* at www.LLS.org/resourcecenter or contact our Information Specialists for a copy.

Long-Term and Late Effects

Long-term effects are medical problems that last for months or years after treatment ends. Fatigue is an example.

Late effects are medical problems that do not show up until years after treatment ends. Heart disease is an example.

Children and adults who have been treated for AML need to see the doctor for follow-up care.

Children who are treated for AML may have

- Growth problems
- Fertility problems (ability to have children later on)
- Bone problems
- Heart problems
- Learning problems.

Adults who are treated for AML may have

- Fertility problems
- Thyroid problems
- Problems concentrating
- Persistent fatigue.

Patients should talk with their doctors about any long-term or late effects that may be related to their treatment. Parents should talk to the doctor about when their child's learning skills should be checked.

Want more information?



You can view, print or order the free LLS publications *Long-term and Late Effects of Treatment for Childhood Leukemia or Lymphoma*; *Long-term and Late Effects of Treatment in Adults*; or *Fertility Facts* at www.LLS.org/resourcecenter or contact our Information Specialists for copies.

Follow-up Care

Medical follow-up is important for every AML patient. At follow-up visits, the doctor will check the patient carefully to see if more treatment is needed.

Children and adults who have been treated for AML should see their primary care doctor and an oncologist (cancer specialist) for follow-up care. Patients should talk to the doctor about how often to have follow-up visits. They can ask what tests they will need—and find out how often to have the tests.

Follow-up care includes physical exams and blood tests. Sometimes marrow tests are also needed. The doctor may advise longer periods of time between follow-up visits if a patient

- Continues to be free of signs of AML
- Does not need medical care for any long-term or late effects.

Tracking Your AML Tests

These tips may help you to save time and to know more about your health:

- Ask your doctor why certain tests are being done and what to expect.
- Discuss test results with your doctor.
- Ask for and keep copies of lab reports and treatment records. Organize test reports by date.
- Find out if and when follow-up tests are needed.
- Mark appointments that are coming up on your calendar.

Take Care of Yourself

- Keep all appointments with the doctor.
- Discuss how you feel with the doctor at each visit.
- People with AML may have more infections. Follow the doctor's advice for preventing infection.
- Eat healthy foods each day. It is okay to eat four or five smaller meals instead of three bigger ones.
- Contact the doctor about tiredness, fever or other symptoms.
- Do not smoke. People who smoke should get help to quit.
- Get enough rest and exercise. Talk with your doctor before starting an exercise program.
- Keep a healthcare file with copies of lab reports and treatment records.
- Have regular screenings for skin, colorectal and (for women) breast cancer.
- See the primary care doctor to keep up with other healthcare needs.
- Talk with family and friends about how you feel. When family and friends know about AML and its treatment, they may worry less.
- Seek medical advice if you feel sad or depressed and your mood does not improve over time. For example, if you feel sad or depressed every day for a two-week period, seek help. Depression is an illness. It should be treated even when a person is being treated for AML. Treatment for depression has benefits for people living with cancer.

Medical Terms

Absolute Neutrophil Count (ANC). The number of neutrophils (a type of white cell) that a person has to fight infection. It is calculated by multiplying the total number of white blood cells by the percent of neutrophils.

Anemia. A decrease in the levels of hemoglobin in the blood.

Antibiotics. Drugs that are used to treat infections caused by bacteria and fungi. Penicillin is one type of antibiotic.

Basophil. A type of white cell that plays a part in allergies.

Blast cells. Early bone marrow cells. About 1 to 5 percent of normal marrow cells are blast cells.

Bone marrow aspiration. A procedure to remove and examine marrow cells to see if they are normal. A liquid sample containing cells is taken from the marrow and then the cells are looked at under a microscope.

Bone marrow biopsy. A procedure to remove and examine marrow cells to see if they are normal. A very small amount of bone filled with marrow cells is taken from the body, and the cells are looked at under a microscope.

Central line. Special tubing the doctor puts into a large vein in the upper chest to prepare a patient for chemotherapy treatment. The central line is used to give the patient chemotherapy drugs and blood cells, and to remove blood samples. Also called an **indwelling catheter**.

Chemotherapy or drug therapy. Treatment with chemical agents to treat AML and other cancers.

Chloroma. A large mass of AML cells, which may be treated with radiation.

Chromosomes. Any of the 23 pairs of certain basic structures in human cells. Chromosomes are made up of genes. Genes give the instructions that tell each cell what to do. The number or shape of chromosomes may be changed in blood cancer cells.

Clinical trials. Careful studies done by doctors for new drugs or treatments or new uses for approved drugs or treatments. The goal of clinical trials for blood cancers is to improve treatment and quality of life and to find cures.

Combination chemotherapy or drug therapy. The use of two or more drugs together to treat AML and other cancers.

Consolidation therapy. Added treatment given to a cancer patient after the disease is in remission. It usually includes chemotherapy drugs not used during induction treatment. Also called **intensification therapy**.

Cytogenetic analysis. The examination of the chromosomes of AML cells to give doctors information about how to treat patients. Cell samples can be taken from blood or marrow.

Diagnose. To detect a disease from a person's signs, symptoms and test results. The doctor diagnoses a patient.

Drug resistance. When a drug used to treat a patient's disease does not work or stops working.

Eosinophil. A type of white cell that plays a part in allergies.

FDA. The short name for the US Food and Drug Administration. Part of the FDA's job is to assure the safety and security of drugs, medical devices and the US food supply.

Flow cytometry. This test is a method of measuring the number of cells in a sample, the percent of cells in a sample, the size and shape of the cell, and the presence of markers on the cell surface.

Hematologist. A doctor who treats blood cell diseases.

Hemoglobin. The part of the red cell that carries oxygen.

Immune response. The reaction of the body to foreign material. Examples of foreign material are an infection-causing microorganism, a vaccine or the cells of another person when those cells are used for an allogeneic stem cell transplant.

Immune system. Cells and proteins in the body that defend it against infection.

Immunoglobulins. Proteins that fight infection.

Immunophenotyping. A lab test that can be used to identify the type of AML cells.

Immunotherapy. The treatments that are used to boost the body's immune system.

Leukemia. A cancer of the marrow and blood.

Lymph nodes. Small bean-shaped organs around the body that are part of the body's immune system.

Marrow. The spongy material in the center of bones where blood cells are made.

Oncologist. A doctor who treats patients who have cancer.

Pathologist. A doctor who identifies disease by studying cells and tissues under a microscope.

Plasma. The liquid part of the blood.

Platelet. A type of blood cell that helps prevent bleeding. Platelets cause plugs to form in the blood vessels at the site of an injury.

Postremission therapy. The treatment given to AML patients after induction therapy. Postremission therapy may have two parts: consolidation (or intensification) and maintenance.

Radiation therapy. Treatment with x-rays or other high-energy rays.

Refractory AML. AML that has not responded to initial treatment. Refractory disease may be disease that is getting worse or staying the same (stable disease).

Relapsed AML. AML that responded to treatment but then returned.

Remission. No sign of the disease and/or a period of time when the disease is not causing any health problems.

Resistance. See Drug resistance.

Signs and symptoms. Changes in the body that show the presence of disease. A *sign* is a change that the doctor sees in an exam or a lab test result. A *symptom* is a change that a patient can see or feel.

Stem cell. A type of cell found in marrow that makes red cells, white cells and platelets.



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REACH OUT TO OUR **INFORMATION SPECIALISTS**

The Leukemia & Lymphoma Society's (LLS) Information Specialists provide patients, families and healthcare professionals with the latest information on leukemia, lymphoma and myeloma.

Our team consists of master's level oncology social workers, nurses and health educators who are available by phone Monday through Friday, 9 am to 9 pm (ET).

Co-Pay Assistance

LLS's Co-Pay Assistance Program helps blood cancer patients cover the costs of private and public health insurance premiums, including Medicare and Medicaid, and co-pay obligations. Support for this program is based on the availability of funds by disease.

For more information, call 877.557.2672 or visit www.LLS.org/copay.



For a complete directory of our patient services programs, contact us at

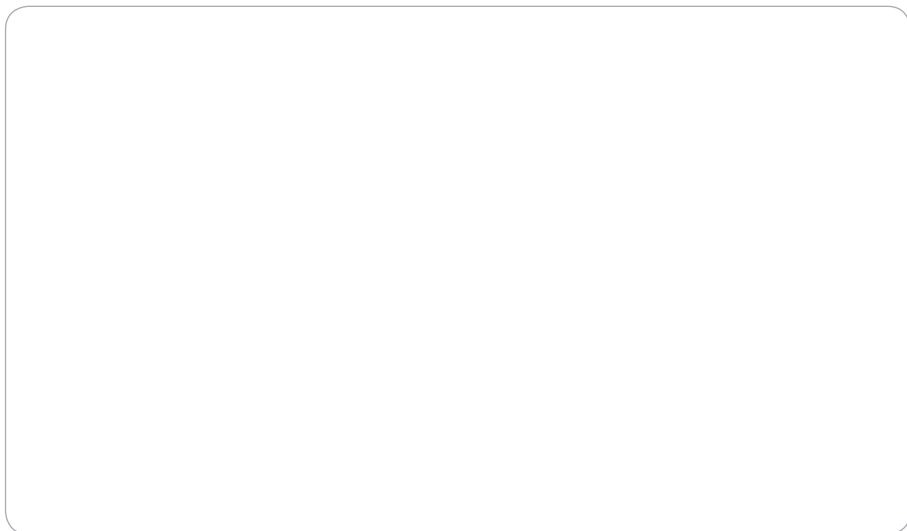
800.955.4572 or www.LLS.org

(Callers may request a language interpreter.)

A large pink triangle is positioned on the left side of the page, with its hypotenuse extending from the bottom-left corner towards the top-right. The text "Pocket Folder" is written in a pink, sans-serif font and is centered within the right-hand portion of the triangle.

Pocket Folder

For more information, please contact:



or:

National Office

1311 Mamaroneck Avenue, Suite 310, White Plains, NY 10605

Contact our Information Specialists **800.955.4572** (*Language interpreters available upon request*)

www.LLS.org

Our Mission:

Cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families.

LLS is a nonprofit organization that relies on the generosity of individual, foundation and corporate contributions to advance its mission.



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